Chapter 5

Transitions for Older Adults with Intellectual and Other Developmental Disabilities (I/DD) and People with I/DD Living with Aging Caregivers

Overview

As the general population ages, so do individuals with intellectual and other developmental disabilities (I/DD) and their parents and other caregivers. Increasing numbers of aging adults with I/DD, supported by aging parents, other family members, or direct support workers present a growing challenge to the I/DD system. As individuals with I/DD age, their health care and other needs often increase at the same time that the ability of their aging support provider decreases. Improvement in and collaboration between health care, life planning, living arrangements, transportation, and other services are needed to ensure that individuals with I/DD receive appropriate and individualized supports as they age. North Carolina must take proactive steps to plan for and deal with these changes to ensure that needed support systems are in place and prepared for the transitions involving adults with I/DD, their families, and a workforce that are aging together.

As individuals with intellectual and other developmental disabilities age, their health care and other needs often increase at the same time that the ability of their aging support provider decreases.

Aging Individuals with Intellectual and Other Developmental Disabilities

The United States population is aging. By 2030, adults age 65 and older will account for 20% of the population, up from 13% in 2000. People 85 years and older comprise the most rapidly growing segment of the US population.[1] In 1998, there were an estimated 526,000 people 60 years or older with a developmental disability in the United States, and this number is projected to double by 2030.[2] It is estimated that between 5,170 and 12,926 North Carolinians with an I/DD are currently over the age of 60.[3]

Although adults with I/DD still have slightly lower life expectancies than the general population, these persons are living significantly longer than just a few decades ago, and many adults with I/DD can now expect to live as long as the general population.[4,5] One of the greatest gains in life expectancy has been for people with Down syndrome. Life expectancy for these individuals has increased from an estimated nine years in 1929 to nearly 60 years today.[5,6]

Experts identify three main criteria of successful aging: the reduction of disease and disability, the maintenance of high cognitive and physical functioning, and active engagement in life.[7] As suggested by this framework, most Americans identify good health, independence, relationships with friends and family, physical health, and remaining connected to the community as markers of successful aging.[8,7] Like all older individuals, people with I/DD want to have a successful aging experience. However, due to a myriad of reasons, these goals may be more difficult for persons with I/DD than for the general aging population. (Specific health care problems and health access issues are discussed more fully in Chapter 6).

Aging Families

Until the mid-1970s, increasing life expectancies among persons with I/DD had relatively little impact on family members and community services, since a large proportion of individuals with I/DD lived in institutional settings.[9] However, deinstitutionalization coupled with new laws and court decisions expanding the rights of persons with I/DD have led to an increasing demand for community services and greatly expanded the number of persons with I/DD who live with their families.[3]

A large number of individuals with I/DD now live with their parents, siblings, or other adults, including direct support workers (DSW). Although it is difficult to determine the exact number, it is estimated that in the United States more than 479,000 adults with I/DD live with parents, age 60 or older, who serve as their primary support provider.[a] The ability of these parents to provide the support needed by family members with I/DD decreases as they grow older.[10,11] As the population ages and life expectancies of persons with I/DD continue to increase, the number of people with I/DD who will experience life transitions, including changes in their physical residence due to the death or diminishing capacity of their support providers, will increase. Many families have not made sufficient plans for this transition.[12]

As the population ages and life expectancies of persons with intellectual and other developmental disabilities (I/DD) continue to increase, the number of people with I/DD who will experience life transitions will increase. Many families have not made sufficient plans for this transition.

Parents of adults with I/DD experience anxiety about what will happen when they are no longer able to provide the services and supports their family member needs. In one study, 74% of family members reported the concern, "what will happen to my relative when I am gone," as being their greatest source of distress.[11] Family members consistently report being troubled by planning for the future well-being of adult children with I/DD. Mothers, in particular, report that these worries have had a negative effect on their health.[13,10] Insufficient planning to ensure the availability of services and supports may thus result in considerable hardship for people with I/DD when families become unable to offer the level of support they previously provided.[14] This process can be extremely trying for all those involved, but advance planning can help alleviate some of the stress and anxiety of the transition from one living arrangement to another.

Older parents of adults with I/DD are likely to need professional help with planning for their adult children's future. Planning can be complex because of the diverse set of needs that must be addressed once the parent, sibling, or other natural support is no longer able to assist the person with I/DD. Parents need information to help them understand the implications of their actions on the well-being of the child with I/DD. For example, a direct inheritance could negatively impact on the child's continued receipt of Medicaid or Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD) services. Parents need to understand the financial

---

[a] Developmental Disabilities Assistance and Bill of Rights Act. 42 U.S.C. 6001 et seq. 2000.

options that do exist to supplement the benefits that the child may be receiving. In addition, the parent may need to arrange for alternative housing if the individual with I/DD cannot continue to live in the family home. Similarly, the parent must arrange for medical care, services, and supports to help the individual with activities of daily living, as well as the provision of legal and financial services. Involving siblings in planning, whenever possible, is important since their insights about their brother or sister and potential resources within the extended family greatly enhance person-centered, future-oriented planning. Despite these concerns, planning among family members for the needs of their adult children with I/DD tends to be inadequate.[9] Many family caregivers of people with I/DD have not discussed future plans with either the person with I/DD or other family members.[9] This may be partly a result of the lack of coordination among different service systems for aging populations and for people with I/DD, lack of information available to families and professionals, and the need for support to families in the development and modification, with the passing of time, of these components of a Person Centered Plan.[3]

Many family caregivers of people with intellectual and other developmental disabilities (I/DD) have not discussed future plans with either the person with I/DD or other family members.

Many older parents do not access services to help in planning even when they are available. In a 1995 study, Smith et al. found that, of older mothers of adults with intellectual disabilities who lived at home, 20% had not yet made plans for the future care of their adult son or daughter, 35% were in some stage of planning, and 45% had made a definite plan.[15] A similar study of parents with adult children with intellectual disabilities found that 31% of the parents had not yet taken steps for future care, 42% were in the process of discussing or making a plan, and 27% had made a definite plan for the care of their family member after they became unable to provide care.[9]

The unexpected death or serious illness of a family member may precipitate a crisis for the person with I/DD, who potentially may be left without housing or other support services. Therefore the Task Force on Transitions for People with Developmental Disabilities recommends:

Recommendation 5.1: Future Planning for Families that Provide Support to People with Intellectual and Other Developmental Disabilities

a) **Local Management Entities (LMEs) and the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMHDDSAS) should help families providing services or supports for people with intellectual and other developmental disabilities (I/DD) with future planning. LMEs should assist families to develop their plans for the future so that the family's and the individual with I/DD's wishes are understood and agreed upon before a crisis occurs. Future planning should include, but not be limited to:**

   1) **An information sheet for families with specific information on the importance of making plans for what will occur when they are no longer able to support their loved one.**

2) A checklist for families about issues they should consider in meeting the future needs of the individual with I/DD, along with a list of available resources in the community that offer services and supports. This information should be made available to individuals with I/DD and their families through the LMEs directly and should be made available on the internet.

3) Options and ideas for paying for some of the future planning expenses including, but not limited to, legal fees or financial planning fees.

4) Plans for how the financial, residential, safety, medical, supports, legal, and social needs of the individuals with I/DD will be met as the parents age and may no longer be able to provide the same level of support

b) DMHDDSAS and LMEs should develop longer-term emergency housing and support options for people with I/DD who need emergency services because of the death or precipitous illness of a family member who provides services or supports.

Preparing the System to Handle the Challenges Posed by Aging Individuals with Intellectual and other Developmental Disabilities and the Families Supporting Them

North Carolina will face a number of challenges in providing for the expanding population of older adults with I/DD and their aging parents and siblings. The state and community support system may become overwhelmed by the demand for services as adults with I/DD currently living in the family home begin to need services or supports from the state-funded I/DD or aging systems.[14,5] The first step is to identify people who are not being served, or who are underserved and link those individuals to existing services and supports. Beyond this, however, the state should identify family-centered policies for improving services and supports for this population, including not only appropriate health care, but also assistance in legal and financial matters, in developing "whole-family" approaches to family support, and in coordinating services among the various agencies from which these families seek assistance.

The state should identify family-centered policies for improving services and supports for older adults with intellectual and other developmental disabilities.

In 2002, the North Carolina Council on Developmental Disabilities, the North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services, the North Carolina Division of Aging, advocates for both older adults and adults with I/DD, service providers, constituents, and social service agencies established The North Carolina Task Force on Aging and Developmental Disabilities (TFADD) to identify areas where the elements of the aging and developmental disabilities services networks can work together to better serve this population.[3] TFADD formulated a number of proposals for addressing the increasing needs of adults with I/DD, particularly by fostering cooperation between the aging and I/DD service networks.

TFADD noted a number of barriers to service access and availability. Among these are the lack of low-cost, reliable transportation to persons in many communities, overspecialization among service providers, lack of knowledge about available services, inadequate funding, and large numbers of older adults with I/DD who remain unknown to the system. TFADD also identified the need to encourage families to seek formal support, the need for support services to address all needs, including emotional needs, of both older adults with I/DD and their families, and the need to address legal issues, including guardianship, faced by this population.[3] Finally, TFADD noted that there is currently a severe shortage of housing for persons with I/DD, as well as a lack of support services for those who live in the community outside of formal supportive housing.[3]

TFADD also identified proposed solutions to these barriers. Among these, TFADD recommended as a first step measure to determine the size of the population in need of cross-cutting services (that is, aging persons with I/DD) and to foster cooperation between agencies and organizations working with either or both of these populations (e.g. aging community or people with developmental disabilities). TFADD also recommended targeted outreach to this segment of the population; provision of information about available services, including legal, financial, and transportation services; the inclusion of family members in decision making regarding adults with I/DD; reform and standardization in the guardianship system; and expanded housing options for adults with I/DD.[3] Therefore the Task Force on Transitions for People with Developmental Disabilities recommends:

Recommendation 5.2: Outreach to Older Adults Who are Providing Support to People with Intellectual and Other Developmental Disabilities (I/DD) and Linkages into the Aging System for Older Adults with I/DD

Local Management Entities (LMEs) should work with appropriate community organizations including, but not limited to, Area Agencies on Aging, senior centers, home health and hospice services, the faith community, and other community groups to:

- **a) Conduct outreach to identify families of individuals with intellectual and other developmental disabilities (I/DD) who are not currently connected to the I/DD system to provide information about the availability of supports and services for people with I/DD and their families.**
- **b) Ensure that older adults with I/DD and their families have appropriate access to the range of services and supports offered by those organizations.**

References

1 Administration on Aging, US Department of Health and Human Services. A profile of older Americans: 2000. http://www.aoa.gov/AoAroot/Aging_Statistics/Profile/2000/profile2000.pdf. Published 2000. Accessed March 10, 2009.

2 Heller T, Factor A. *Older Adults with Mental Retardation and their Aging Family Caregivers.* Chicago, IL: Rehabilitation Research and Training Center on Aging with Developmental Disabilities; 2004.

3 Folts WE, Baumhover LA. *Aging and Developmental Disabilities: A Blueprint for Change, Report of the North Carolina Task Force on Aging and Developmental Disabilities.* North Carolina Task Force on Aging and Developmental Disabilities; 2001.

4 Patja K, Iivanainen M, Vesala H, Oksanen H, Ruoppila I. Life expectancy of people with intellectual disability: a 35-year follow-up study. *J Intellect Disabil Res.* 2000;44 (Pt 5) (Pt 5):591-599.

5 Janicki MP, Dalton AJ, Henderson CM, Davidson PW. Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disabil Rehabil.* 1999;21(5-6):284-294.

6 Glasson EJ, Sullivan SG, Hussain R, Petterson BA, Montgomery PD, Bittles AH. The changing survival profile of people with Down's Syndrome: implications for genetic counseling. *Clin Genet.* 2002;62(5):390-393.

7 Rowe JW, Kahn RL. Human aging: usual and successful. *Science.* 1987;237(4811):143-149.

8 Phelan EA, Anderson LA, LaCroix AZ, Larson EB. Older adults' views of "successful aging"—how do they compare with researchers' definitions? *J Am Geriatr Soc.* 2004;52(2):211-216.

9 Heller T, Factor A. Permanency planning for adults with mental retardation living with family caregivers. *Am J Ment Retard.* 1991;96(2):163-176.

10 Cook JA, Lefley HP, Pickett SA, Cohler BJ. Age and family burden among parents of offspring with severe mental illness. *Am J Orthopsychiatry.* 1994;64(3):435-447.

11 Lefley HP, Hatfield AB. Helping parental caregivers and mental health consumers cope with parental aging and loss. *Psychiatr Serv.* 1999;50(3):369-375.

12 Smith GC. Predictors of the stage of residential planning among aging families of adults with severe mental illness. *Psychiatr Serv.* 2004;55(7):804-810.

13 Greenberg JS, Reenley JR, McKee D, et al. Mothers caring for an adult child with schizophrenia: the effects of subjective burden on maternal health. *Fam Relat.* 1993;42:205–211:205-211.

14 Smith GC, Hatfield AB, Miller DC. Planning by older mothers for the future care of offspring with serious mental illness. *Psychiatr Serv.* 2000;51(9):1162-1166.

15 Smith GC, Tobin SS, Fullmer EM. Elderly mothers caring at home for offspring with mental retardation: a model of permanency planning. *Am J Ment Retard.* 1995;99(5):487-499.